DOCUMENT RESUME

ED 196 190 EC 131 317

AUTHOR Suelzle, Marijean; Keenan, Vincent
TITLE Outlook for Families with Developmentally Disabled Children in the 1980's.
SPONS AGENCY Illinois State Dept. of Mental Health and Developmental Disabilities, Springfield.
PUB DATE Oct 80
NOTE 27p.; Paper presented at the Annual Meeting of the Illinois Sociological Association (Chicago, IL, October 24, 1980). For related information, see EC 131 316 and EC 131 318.

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS *Adjustment (to Environment); *Community Attitudes; *Community Resources; Deinstitutionalization (of Disabled); *Developmental Disabilities; Exceptional Child Research; Family Relationship; *Normalization (Handicapped)

ABSTRACT

The home and community adjustment of 325 families with developmentally disabled children 21 years of age or younger was examined through questionnaire responses. Factors facilitating adjustment are identified along with barriers to normalization. It is suggested that without community support over the life cycle, institutionalization may merely be postponed from childhood to adulthood. Conclusions focus on the changes necessary in community attitudes and resources to prevent institutionalization of these children as they reach adulthood. (Author/CL)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED196190

U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
NATIONAL INSTITUTE OF EDUCATION
THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY

Outlook for Families with Developmentally Disabled Children in the 1980's*

Marijean Suelzle
Department of Sociology
Northwestern University
Evanston, Illinois 60201

and

Vincent Keenan
School of Public Health
University of Illinois at the Medical Center
Chicago, Illinois 60680

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
Marijean Suelzle
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

EC 131317

*Presented at the Annual Meeting of the Illinois Sociological Association, Chicago, Illinois, October 24, 1980. The research was supported in part by the Extramural Research and Development Grants Program of the Illinois Department of Mental Health and Developmental Disabilities.

ABSTRACT

This paper examines the home and community adjustment of families with developmentally disabled children 21 years of age or younger (i.e., children with mental retardation, cerebral palsy, epilepsy, or autism). Data collected from a mail questionnaire completed by 325 families in Lake County, Illinois during the late 1970's reveals both factors facilitating adjustment and barriers to the principle of normalization. In the absence of community support over the life cycle, institutionalization may merely be postponed from childhood to adulthood. The paper identifies the types of changes necessary in community attitudes and behaviors during the 1980's to prevent the institutionalization of these children upon their reaching adulthood.

INTRODUCTION

In 1975, with the passage of the Education for All Handicapped Children Act (Public Law 94-142), it was estimated that one-half of the nation's eight million handicapped children were not receiving an appropriate education. About one million of these students were excluded from the public school system entirely and many were institutionalized. The law provides that all handicapped children between three and twenty-one years of age have available to them a free appropriate public education. The philosophy of institutionalization has given way to community based programs. Families are expected to rear their handicapped children at home, and the children are expected to be educated with their nonhandicapped peers to the maximum extent possible. As this change in educational philosophy is implemented, the social world of the handicapped child becomes defined by the child's integration into family activities, and the family's integration into the community.

As the mediator between the individual and society, the family is the basic social institution. It interprets society's rules of conduct for its members. Yet the term, family, subsumes a wide range of diversity in structure, function, values, and lifestyles. The services that the family provides for its members, other than the affectional, have been transferred to outside agencies with the advent of industrialization and urbanization (Winch, 1971). Of particular importance, responsibility was transferred from home to school for increasing portions of the child's education. The family provides the child with a place in society, with an ascribed social position, to which a

developmental set of expectations are attached. The educational system generalizes these expectations by age-grade levels to establish a standardized set of achievement norms which all children are expected to attain in order for their socialization and development to proceed as projected. The handicapped child cannot attain all of the complex cognitive, physical, social, and emotional developmental achievement norms prescribed by the generalized educational system. For the handicapped child, generalized norms must be replaced with ones which are more particularistic and individualistic. The extent of the child's disability, available alternatives, and the parents' emphasis on the importance of the generalized achievement norms will determine the nature of the particularistic and individualistic resolution sought.

Structurally the family is a unit which performs the functions of nurturance and control to enable the child to survive and avoid the hazards of the environment. Performance of the nurturance and control functions is facilitated or impeded by both the activity level of the child and the availability of assistance with the child's care. As these maintenance functions are fulfilled more easily then the emphasis on emotional bonds becomes more important. Healthy families provide their members with psychic, status, and interpersonal security. They provide emotional gratification and self-esteem based upon recognition of and affection for the unique individual strengths of each member, rather than the impersonal competitive criteria of the marketplace. The family is an interaction process in which individuals learn and practice roles appropriate for life cycle development. The degree to which families optimize emotional gratification and self-esteem depends upon the relative ease with which maintenance functions can be fulfilled. As main-

tenance functions are fulfilled, family members are enabled to participate in the usual activities of their relevant social networks.

Community attitudes are an important factor in the disabled child's development. They may mediate, augment, or deemphasize the impact of the disability - ranging from revulsion, condemnation, and avoidance to tolerance, altruism, love, and hope. Identifying community reactions is important in understanding the family's integration into the community. Normalization relates to the belief that an individual should be allowed to live his/her daily existence in a style that is similar to those in the surrounding community as is sex and age appropriate (Wolfensberger, 1972: 28). Normalization is analogous to the maintenance of health rather than the treatment of sickness and disease. It requires the integration of support systems at an appropriate pace for the handicapped child just as the public school system is appropriately paced for the age-graded development of the normal child toward economic and social self-sufficiency. This implies that the family alone cannot provide a normalized environment for a handicapped child. Neighbors and members of the general public with whom the family would come into contact in the everyday course of events must also accept the handicapped child. If community acceptance is not forthcoming and the child is isolated from regular experiences in preparation for adulthood, then the social world beyond the family becomes inaccessible. In the absence of community support over the life cycle, institutionalization may merely be postponed from childhood to adulthood.

This paper utilizes data collected in the late 1970's to examine the ability of families to provide a normalized environment for developmentally disabled children. Two dimensions are explored--the ability of families to

meet social and emotional needs within the home, and the ability of families to provide the entire range of community interactions which would ordinarily be part of the childhood and adolescent experience. The ability of the family to function within these two spheres -- home and community -- is projected to suggest the outlook for similar families in the 1980's.

RESEARCH METHODS

Sampling Procedures

The population was defined as Lake County, Illinois, parents of developmentally disabled children ages 0-21 who receive services in Lake County. For the purposes of this study, developmentally disabled is defined as children handicapped by mental retardation, cerebral palsy, epilepsy, autism, or multiple handicaps involving one or more of the foregoing, and whose handicap required more than 50 percent time in a special education program. Extensive correspondence and discussion with agencies at the State and local levels, as well as with individual facilities and parents contacted through the Illinois Governor's Advisory Council on Developmental Disabilities and local organizations, resulted in the identification of 751 families. Because of adherence to regulations governing rights of privacy, mailings requesting parents to consent to participate in the study went out through the educational facilities serving Lake County: Three special education school districts, a state residential facility, a federally funded early intervention program, and six private facilities. Due to the low percentage of consents received after the first mailing (37.7 percent) these educational facilities also conducted a follow-up mailing.

Data Collection Procedures

A computerized review of the literature and open-ended depth interviews with parents were used to construct a mail survey questionnaire. The questionnaire was pretested with 66 families of children attending three schools for the developmentally disabled in Evanston, Illinois. Following revisions based upon the pretest results, a 57-page mail survey questionnaire was developed for the Lake County population. Structured closed-ended questions were designed to provide data regarding:

--the manner in which parents first discovered that their child was developmentally disabled;

--the availability of extended family and community support networks for the parents and their children;

--the nature of the developmental disability, skill levels, and kinds of limits the children have;

--the manner in which parents successfully or unsuccessfully secure the community services needed by their developmentally disabled children;

--the current professional intervention encountered and its perceived value;

--parents' attitudes regarding the direct services currently used for their children;

--parental involvement in their children's educational programs and organizations concerned with developmental disabilities;

--parents' opinions about general policy directions for the provision of services for the developmentally disabled in their community; and

--long-term plans and objectives these parents have for their children.

Questionnaires were mailed out over the three-month period from mid-March to mid-June 1978 to the 458 families (61.0 percent) who finally consented to participate. Included with each questionnaire mailed was a return post card with the respondent's name and the statement, "I have mailed my completed

questionnaire." Respondents were asked to mail the card, separately, at the same time they mailed the completed questionnaire. Since the questionnaires themselves were filled in anonymously, the post cards were our only check on which consenting parents had, in fact, returned questionnaires. A follow-up letter with a second return post card was sent approximately one month after the questionnaire was mailed if we had not received a post card notifying us of its return before that time. These procedures resulted in the return of 330 completed questionnaires (43.9 percent of the families identified and contacted; 72.1 percent of the families who consented to participate).

Returned questionnaires were coded and keypunched and a file defined for statistical analysis of the data with the Statistical Package for the Social Sciences (SPSS) system of computer programs. The data was cleaned by eliminating out-of-range errors and performing a series of contingency checks.

Characteristics of Parents and Their Children

The study was conducted in Lake County, Illinois. The county is in close proximity to Northwestern University, which minimized travel time and expense. Lake County offers a wide range of services to developmentally disabled persons. There is a major state-operated residential center for severely and profoundly retarded persons. There are other smaller residential programs operated by private non-profit groups. The county is known for its comprehensive programs of special education offered through the public school districts. There are several sheltered workshop facilities for developmentally disabled persons. Within the area alternative residential programs for developmentally disabled persons are beginning to be developed (e.g. community

living facilities, foster home networks, group homes).

The area of Lake County was selected for the research population because: (1) it is geographically compact yet includes urban, suburban and rural populations; (2) it offers a wide variety of services for the developmentally disabled; (3) providers and consumers of developmentally disabled services have a history of cooperation with past efforts to secure related information; and (4) the county contains people of wide range of socioeconomic, ethnic and racial backgrounds.

Although the questionnaires were mailed to both parents in two-parent families, almost all were completed by the children's mothers. Of these mothers, 20 percent had not completed high school, 33 percent were high school graduates, 31 percent had some college or special career taaining, and 16 percent were college graduates. In 1978 dollars, 33 percent had yearly family incomes before taxes of less than $15,000, 39 percent between $15 - 25,000, and 28 percent over $25,000. The vast majority (86 percent) were currently married; that is, most children in the study were from two-parent homes. About half of the mothers (48 percent) were employed outside the home, a group about equally divided between those holding full-time and part-time jobs. In terms of racial composition, 83 percent of the sample were white, 11 percent black, 3 percent Latino, and 3 percent Asian or American Indian.

Of the children reported on in the questionnaires, 21 percent were identified by their parents as mildly retarded, 34 percent as moderately mentally retarded, 20 percent as severely and profoundly mentally retarded, 12 percent as having cerebral palsy, 4 percent as autistic, and 9 percent as having epilepsy. Of the children, 57 percent were male and 43 percent, female.

FINDINGS

Adjustments Within the Nuclear Family

Having a developmentally disabled child in the family affects mothers and fathers individually, as well as their marriage. The extra attention that a developmentally disabled child requires can result in an intensified emotional environment, potentially either positive or negative. In our sample, the mutual adjustment of nuclear family members seems to enable the vast majority of families to meet members' needs for love and belonging (see Table 1).

TABLE 1 ABOUT HERE

In terms of the positive expression of affection, mother-child interactions are perceived as more unambiguously rewarding than wife-husband interactions. Almost all mothers (84.5%) consider time with their children well spent and very few disagree (4.7%). The majority (64.3%) are satisfied with the amount of remaining time to be spent alone with their husbands, although nearly one-quarter feel that time available to be spent alone with husbands is insufficient. The importance of spending time with their developmentally disabled children does seem for some to curtail the amount of time available to be spent alone with husbands.

Spending time with children is perceived as important because it enhances children's development. The time spent with children can be perceived as either enhancing or curtailing the parents' development. That is, there can be mutually beneficial effects. On the other hand sacrifices of time and money made by the parents may be such that only the child is felt to

benefit. For our sample, the special efforts required for a developmentally disabled child are clearly perceived as more beneficial to parents' personal growth and autonomy than not. Mothers typically invest a greater amount of time than do fathers and they correspondingly perceive more personal growth as a result of the experience (63.3% for mothers compared to 52.6% for fathers). The remainder are more likely to be uncertain whether the developmentally disabled child made a difference in their personal growth than to feel the child had been a constraint.

Intensification of demands can result in greater satisfaction and rewards but also greater frustration and isolation. For our sample satisfaction greatly outweighs frustration. Only 14.7% of the mothers feel trapped at home, and a slightly smaller number have ever become so frustrated that they wish their children would die (11.5%). Wives are less certain about the intensity of their husbands' frustrations, although an equally large number (84.7%) disagree that either they or their husbands have ever wished their children would die.

Having a developmentally disabled child in the family can affect the types of adaptations which families must make to the world outside the nuclear units (see Table 2). Social and geographical mobility may be inhibited for two reasons. Investment of the time and money required to meet a developmentally disabled child's educational and medical needs may result in less resources available to be invested in career development. A relative lack of services in other geographical areas of the country may prohibit taking a job in a different area. On the other hand, needs for more income may spark career development. Experiences gained in working with developmentally disabled children can expand skills and social contacts which can in turn be

translated into career opportunities. Families may have moved to Illinois to take advantage of better educational services than were available elsewhere.

TABLE 2 ABOUT HERE

In our sample, the net perceived effect of the developmentally disabled child on career and job mobility seems to be roughly equivalent. A small number of parents (14% or less) perceive their children to have impeded or to have advanced career success or job opportunities. The vast majority perceive the child to have had no effect (88% perceive no effect on husband's career, 74% on wife's career, and 81% on job mobility).

Community involvement beyond the sphere of work can also be inhibited by having a developmentally disabled child in the family. Developmentally disabled children need closer supervision for a longer period of their lives than do normal children. Some parents are, therefore restricted in the amount of time available to pursue other interests. Expenses for associated medical services can reduce discretionary income. In our sample, very few mothers perceived their children as having negative effects on their political or religious involvement (3.9% and 6.1%, respectively). A slightly larger number felt their children had negative effects on entertaining people at home or on social activities outside the home (13.9% and 20.9%, respectively).

Some parents become more involved in the community by participating in self-help support groups. These groups are associated with most on-going services (such as, educational and residential programs) and are involved in advocacy as an outgrowth of sharing experiences and information. Substantially

more mothers felt their children had positive effects on their political involvement than negative (18.3% vs. 3.9%). Parents can become involved in supporting special religious education for their children as well as deepening their own religious commitment. Again, developmentally disabled children were overwhelmingly perceived to have more positive than negative effects on religious involvement (34.1% vs. 6.1%). Effects on parents' social activities both within and outside their homes are more even. About as many perceive their children to have had positive as to have had negative effects.

The impact of developmentally disabled children on parents' lives is one thing. Involvement of the children in family activities is another. In the philosophy of normalization, the family is the most important provider of community-based activities since children spend more time with families than in educational environments. Virtually all children are included in such everyday family activities as going for car rides, visiting friends or relatives, taking walks, and eating out (see Table 3). Children with severe communication disabilities may be unable to engage in ordinary pastimes, like watching TV. Children are more likely to be excluded, or the family as a unit is less likely to participate, when activities would require group participation of a scheduled duration (that is, going to movies, sports events or religious services).

TABLE 3 ABOUT HERE

Extended Family and Community Networks

In the previous section, we have shown that the nuclear family can and does adjust well to having a developmentally disabled child. Participation

in group activities outside the nuclear family does become problematic, both for parents and for the family as a unit. Within the nuclear family unit the burden of socialization and education activities for the mother can be reduced by assistance from others (see Table 4). Help is, in fact, received from other nuclear family members in a bare majority of cases (from the child's siblings in 57.7% of families and from fathers in 56.0%). Next most likely to be of assistance are extended family members (24.0%). Beyond the ties of kinship, friends and neighbors are only about as likely to be of assistance to mothers as professionals (in 15.8% and 13.9% of families, respectively). In summary, nuclear families seem to be autonomous, yet isolated, in the provision of care for the developmentally disabled child.

TABLE 4 ABOUT HERE

Caring for a child can be construed more broadly than the provision of regular assistance with developmental tasks. Children do receive regular skills instruction within a school environment, so these needs are at least partially met. Even though children benefit if instruction is complemented by efforts in the home, perhaps, it is of greater importance that the family functions to meet children's emotional needs. As long as the nuclear family can function on a daily basis, regular assistance may be less important than statements of love and interest from extended family members. These statements may help the nuclear family best fulfill its expressive function. Knowing that the child is at least accepted as a desireable member of the kinship system may reinforce the family's sense that what is being done with the child is worthwhile. Knowing that help with caring for the child would be

available when needed may be as psychologically comforting as receiving help on a regular basis.

The strongest bonds of both affect and duty within the extended family are among children, parents and grandparents. Two ways that affective bonds are expressed are through symbolic representations of the family, such as photographs, and in family rituals, such as those surrounding birthdays. Grandparents, in our sample, were overwhelmingly reported as expressing affection for the children in these ways (see Table 5). Very few grandparents were reported as not enjoying photographs of the child or remembering the child's birthday. Affective bonds can also be expressed more concretely by the willingness of grandparents to provide a back-up system, such as providing parents a break from routine daily activities or in cases of illness. Far fewer families reported that they could rely on grandparents to provide this type of back-up system. Nearly one-half (47.6%) could invariably rely on grandparents and 19.6% could hardly ever do so.

TABLE 5 ABOUT HERE

If families are to be supported in caring for developmentally disabled children at home then acceptance by neighbors is important, as is acceptance by extended family. At least nuclear families have somewhat more freedom in selecting neighbors than in selecting relatives with whom they will interact.

Labeling a developmentally disabled child as deviant may result in both the child and the family being isolated from regular social contacts with neighbors. Increased social distance and isolation can occur as a result

of the family's withdrawal from social interactions as well as because others exclude the family and child from their social activities (see Table 6).

TABLE 6 ABOUT HERE

Deviation from normative developmental expectations becomes more pronounced as children mature. Therefore, the adolescent or adult with a developmental disability is more likely to have behaviors which deviate from those ordinarily expected in group settings. In order to ascertain differences in acceptance over the life cycle, age of the child was introduced as a control variable. Four stages in the life cycle of the developmentally disabled children in the study are defined: preschool (birth to 5 years old), elementary (6 to 12 years old), teenage (13 to 18 years old), and young adult (19-21 years old).

Regardless of the child's age, if parents are willing to initiate social invitations, most perceive their neighbors as willing to visit when their developmentally disabled children are at home. That is, families do not express a greater tendency to withdraw from social activities over the life cycle.

In contrast, actions which require initiative on the part of neighbors are perceived to become less likely over the life cycle. From the family's point of view, social isolation of the child in the community appears to result more from exclusion than from withdrawal. The problem becomes more acute as the child nears adulthood and the period of formal education ends. For the normal child this would be the time the child would leave home to

undertake further training, jobs and marriage. Due to the limitations imposed by their disabilities, and a relative paucity of appropriate vocational opportunities, many parents of developmentally disabled children are faced with the probability that their adult children will remain at home requiring on-going care. The physical and emotional demands made by the adult child are greater than those of the young child, while at the same time there is less community support. Despite the emphasis on mainstreaming and community-based services, residential care may be the only option to that of maintaining the developmentally disabled adult at home in the status of dependent child.

Over the life cycle, we do find that parents increasingly accept the inevitability of residential placement if they became unable to care for their children (see Table 7). Correspondingly fewer parents over the life cycle report that care would be provided by family or friends.

TABLE 7 ABOUT HERE

DISCUSSION

Nuclear families with developmentally disabled children have adjusted well to the expectation that their children will remain at home. Whatever hopes and aspirations were modified in the light of severe developmental limitations, individual strengths and accomplishments appear to be valued within the family setting. Emotional needs of the children and the parents are largely met. Extra time required is not resented. The children are much more likely to be viewed as assets to personal growth and family functioning rather than as liabilities. Support is forthcoming from extended family members and others in meeting emotional needs as reflected

beyond the structured questionnaire in parents' comments:

> We have been most fortunate in having kind-hearted, sympathetic and understanding friends and relatives. They were educated along with us and have not been made to feel uneasy or uncomfortable in any situation or surroundings. We have also received a great deal of encouragement from them.

> The attitude changes of all those involved by knowing a retarded child are remarkable. Most people I have met and become good friends with and do not have retarded children seem to grow in their awareness of the value of life. They tend to stop and think of the importance of time and slow down in their rat race of living to appreciate what they have.

However, the extra time required by a developmentally disabled child curtails interactions between family members. The ability of the family to include the child in public activities is limited. The vast majority of nuclear families bear the entire burden of the child's disability without assistance. The nuclear families are self-sufficient, yet the children tend to be isolated within the families except for that part of the day when they are attending school. Even grandparents are much more likely to be emotionally supportive than to provide a reliable source of assistance when needed. The nuclear families tend to become isolated from social interactions outside the home too as other parents comments show:

> We are more or less by ourselves. We can't go with him too many places. Not too many people are willing or able to babysit with him. And we couldn't afford it too much anyhow. His brother and sister don't want much anything to do with him. They may babysit with him when it's really necessary. We don't have too many friends or relatives come to visit us.

> Many friendships ceased to exist. Some people were afraid their children would "catch it", too. Some of our "normal" child's friends couldn't visit at our home because of our d.d. child.

Neighbors are increasingly less likely to accept developmentally disabled children in age-appropriate situations as the children grow up from early childhood to young adulthood. Nuclear families are inhibited from providing

their children with the experience necessary to adapt to the social world outside the home. Usually family life provides for a series of separations, apart from formal education, which help prepare children for adult autonomy. Children may require adult supervision during these separations but usually this responsibility is not borne so exclusively by the parents.

For developmentally disabled children there are few activities outside school to provide a structure for their lives outside their nuclear families. Once schooling ends there are few vocational opportunities to fill the gap. Nuclear families appear to be very capable of providing the necessary emotional support for personality development, but cannot independently provide productive functions. If the limited community opportunities do not meet an individual young adult's needs, then the family has two alternatives: keep the young adult at home in the status of dependent child or institutionalize. The family has become a specialist in a world of specialists, but the family has extended its specialization to incorporate an individual with a disability to a greater extent than has the community. Unless the community modifies its expectations for adulthood, and provides work and residential options accordingly, then families cannot prepare their developmentally disabled children for emancipation except for institutionalizing. Parents' anguish about this dilemma is eloquently expressed in the following representative comments:

> Children who are normal grow up and leave home at about this time. It would be unfair to our child to keep him at home without friends and activities.

> We plan to have our child finish his special education years and then see what the possibilities are for his future. We would like to place him in a permanent home while we are still healthy and able to visit him and have him home for vacations. After his schooling is finished, we feel he will truly miss his friends, all DD individuals, and would be happier in a residential or community living placement before an emergency arises and he has to be abruptly uprooted from home. We don't know at what age this will be.

> Our child will finish school at 21. Her brother and sisters will most likely not be living at home. Her father and I will be in our 50's. I think if a good residential placement could be found it would be to everyone's advantage. I think at age 21, our child will want friends, a social life, etc., that we will not be able to provide and the community cannot provide at this time.

Change in community attitudes and policy will be necessary in the 1980's to continue the integration of developmentally disabled adults into the community. Normalization has not been achieved when home and school cannot work together to prepare developmentally disabled children to live as adults with the greatest amount of autonomy possible. At the present time institutionalization is being postponed, not eliminated. The outlook for the '80's is bleak unless communities begin to provide residential and vocational opportunities which maximize independence by reducing the dependency of developmentally disabled adults on either nuclear families or institutions.

References

Winch, Robert F.
1971 The Modern Family. Third Edition. New York: Holt, Rinehart and Winston.

Wolfensberger, Wolf
1972 The Principle of Normalization in Human Services. Toronto, Canada: National Institute on Mental Retardation.

Table 1. Effect of developmentally disabled child on family satisfaction. (rank ordered by agreement)

Satisfaction with Interactions	Agree	Uncertain	Disagree	
I consider my time with this child to be well spent.	84.5%	10.7	4.7	N = 317
I'm satisfied with the amount of time I'm able to spend alone with my husband.	64.3%	11.8	23.9	N = 272*
Parents' Personal Development				
Having a developmentally disabled child has made me a better person.	63.3%	23.5	13.2	N = 319
Having a developmentally disabled child has made my husband a better person.	52.6%	29.2	18.3	N = 274*
Isolation and Frustration				
I feel "trapped" at home because of my developmentally disabled child.	14.7%	13.8	71.4	N = 312
Sometimes I've become so frustrated by problems caused by the developmental disability that I've wished our child would die.	11.5%	3.8	84.7	N = 314
Sometimes my husband has become so frustrated by problems caused by the developmental disability that he's wished our child would die.	3.7%	11.7	84.7	N = 273*

* Answered by married respondents only.

Table 2. Effect of developmentally disabled child on career mobility and community involvement. (Rank ordered by perceived negative effect)

Career Mobility	Negative	No Effect	Positive	
Your husband's making a success of his career.	4.5%	88.1	7.4	N = 270*
Making a success of your career.	12.7%	74.1	13.3	N = 158**
Moving the family for new job opportunities.	13.6%	81.1	5.3	N = 301
Community Involvement				
Political involvement.	3.9%	77.8	18.3	N = 311
Religious involvement.	6.1%	59.8	34.1	N = 311
Entertaining people in your home.	13.9%	73.5	12.6	N = 309
Involvement in social activities outside your home.	20.9%	50.0	29.2	N = 312

* Answered by married respondents only.

** Answered by working mothers only.

Table 3. Involvement of developmentally disabled children in family activities. (rank ordered by frequency of involvement)

	Child does with family	Child does not do with family	Family does not do	
1. Go for rides in the family car	96.6%	1.8	1.6	N = 319
2. Visit friends or relatives	95.6%	4.4	0.0	N = 318
3. Take walks, go to beach, or park, or similar activities	91.4%	5.4	3.2	N = 315
4. Eat away from home (for example, ice cream parlors, hamburger stands, or restaurants)	90.2%	6.9	2.9	N = 317
5. Watch TV	87.1%	11.3	1.6	N = 318
6. Go to movies, concerts, plays, sports events, or similar activities	65.2%	24.5	10.3	N = 319
7. Go to church or temple (including Sunday School)	56.3%	17.3	26.4	N = 318

Table 4. People who regularly spend extra time outside school with children on developmental activities. (rank ordered by frequency help given)

	% Yes (N = 317)
1. Child's brothers or sisters	57.7%
2. Your husband	56.0%
3. Child's grandparent or other relative	24.0%
4. A friend or neighbor	15.8%
5. A professional (for example, a physical therapist, a tutor)	13.9%

Table 5. Involvement of grandparents* of developmentally disabled children, (rank ordered by type of involvement)

	Always	Sometimes	Hardly Ever	
1. Enjoy having and looking at photographs of the child	84.6%	13.2	2.2	N = 272
2. Remember the child's birthday	86.2%	10.4	3.3	N = 269
3. Offer to care for the child for short periods when appropriate	47.6%	32.7	19.6	N = 275

* Questions answered only by respondents for families in which at least one grandparent was alive.

Table 6. Percent of respondents perceiving neighbors as accepting child under various circumstances.

	Preschool	Elementary	Teenage	Young Adult
Visit us when developmentally disabled child home	89.3	86.5	90.5	87.2
Accept child as friend for own children of same age	79.0	57.1	54.3	48.9
Invite to visit in their homes	77.0	64.6	57.8	68.1
Accept as neighbor in community living facility upon reaching adulthood	71.6	54.1	61.6	61.7
Accept child as friend for own children of opposite sex	68.9	38.8	40.2	38.3
Accept as classmate at same school as own children	66.7	47.4	47.9	44.4
Accept as coworker upon reaching adulthood	66.2	47.9	45.7	51.1
Accept as adult with full legal rights	60.3	35.8	36.5	37.8
100% =	(76)	(101)	(99)	(47)*

(323)

MD = (7)

* Actual N's fluctuate somewhat due to missing data on the social distance questions.

Table 7. Arrangements anticipated if parents became unable to care for their developmentally disabled children.

	Preschool	Elementary	Teenage	Young Adult
Care would be provided by family or friends	79.4%	70.6%	54.[illegible]%	57.2%
Care would be provided in a residential facility	10.3	12.6	27.9	35.7
I live from day-to-day and trust the future will look after itself	10.3	16.8	17.2	7.1
	100.0% (68)	100.0% (95)	100.0% (93)	100.0% (42)